

Couples' willingness to donate embryos for research: a longitudinal study

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Key words

Cryopreserved embryos, decision making, embryo disposition, in vitro fertilization, longitudinal study, patient-centred care

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Conflict of interest

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Abstract

Introduction. Decision-making on embryo disposition is a source of distress and is subject to change over time. This paper analyzes the willingness of couples undergoing in vitro fertilization to donate cryopreserved embryos for research from 15 days after embryo transfer to 12 months later, taking into account the influence of psychosocial, demographic, and reproductive factors. **Material and methods.** Prospective longitudinal study, with 74 heterosexual couples undergoing in vitro fertilization in a public fertility centre in Portugal, recruited between 2011 and 2012. Participants were evaluated twice: 15 days after embryo transfer and 12 months later. **Results.** A significant decrease in patients' willingness to donate embryos for research over time was observed [86.5% to 73.6%; relative risk (RR) = 0.85; 95% CI 0.76–0.95]. A higher education level (>12 years) [adjusted RR (RR_{adj}) = 0.79; 95% CI 0.64–0.96], considering research on human embryos to be important (vs. very important) (RR_{adj} = 0.59; 95% CI 0.39–0.85) and practicing a religion less than once a month (vs. at least once a month) (RR_{adj} = 0.73; 95% CI 0.53–1.00) seemed associated with unwillingness to donate embryos for research over time. Change towards non-donation happened mainly among couples who first considered that it was better to donate than wasting the embryos. Change towards donation occurred mostly among those stating that their priority at time 1 was to have a baby and who became pregnant in the meantime. **Conclusions.** Quality of care guided by patients' characteristics, values, preferences, and needs calls for considering the factors and reasons underlying couples' willingness to donate embryos for research over time as a topic in psychosocial guidelines for infertility and medically assisted reproductive care.

Abbreviations: ICSI, intracytoplasmic sperm injection; IVF, in vitro fertilization; RR_{adj}, adjusted relative risk; RR, relative risk.

Introduction

Couples undergoing in vitro fertilization (IVF) are asked, in several countries, to sign an informed consent form regarding embryo donation for research. This entails a decision involving both members of the couple, who are

requested to make it together. Differences in regulations, guidelines and healthcare policies between countries determine whether the informed consent should be signed before the first treatment (1), during treatment (2), or after treatment is completed (3). Patients' needs for information and support are likely to vary across these three treatment stages (4), which means that the timing set to

obtain consent is likely to influence the type of decisions made. Hence, obtaining knowledge on how patients' attitudes about embryo disposition evolve over time is needed to guide patient-centredness in infertility and medically assisted reproduction.

Decision-making on embryo disposition is described as being difficult, as well as a source of moral and emotional distress (5,6). Some couples report high decisional conflicts (7) and some delay the decision for as long as possible (5). Yet others report feeling pressure to make a decision (8). Research also suggests that decisions on embryo disposition are subject to change over time (9–11). A study carried out in Belgium observed a positive trend towards embryo donation for research over time (11). Yet other studies carried out in the USA and in Canada found that patients who first chose to donate embryos for research later changed their choice to use or discard embryos (9,10). Having experienced a live birth was associated with discarding embryos rather than using them for research purposes in Canada (10), but studies in France and the USA found no significant association between change in willingness to donate embryos for research and having a child (9,12).

From the few existing longitudinal studies about the factors associated with patients' willingness to donate embryos for research, none focused on the influence of psychosocial, demographic, and reproductive characteristics. Therefore, the objective of this longitudinal study was to analyze the willingness of couples undergoing IVF to donate cryopreserved embryos for research from 15 days after embryo transfer to 12 months later, taking into account the influence of psychosocial, demographic, and reproductive factors.

Material and methods

This is a prospective longitudinal study. Between August 2011 and August 2012, all patients undergoing IVF or intracytoplasmic sperm injection (ICSI) in one reproductive medicine centre in Porto, Portugal, were consecutively and systematically invited to participate in a study on embryo disposition (time 1) and reevaluated 12 months later (time 2). The fertility centre is located in a public University Hospital that carries out IVF-ICSI homologous cycles and does not conduct research projects using human embryos. In Portugal, these techniques are available for heterosexual couples, married or living together for at least 2 years (13). The state pays for IVF-ICSI treatments, embryo freezing, and storage, for up to three cycles per couple, and covers 69% of the total cost of infertility medication (13). Couples with cryopreserved embryos are required to make a joint consensual decision about embryo disposition, saying "Yes" or "No" to

donation to other infertile couples and to scientific research (14). For this reason, participants were asked as a couple whether they would donate embryos for research at time 1 (about 15 days after embryo transfer). Embryos should be used within a maximum period of 3 years, otherwise, embryos will be thawed and discarded. The consent might be unilaterally revoked by either member of the couple. Taking this into account, obtaining data on the individual opinion of the members of the couple at time 2 is fundamental to assess change in willingness to donate embryos for research.

Of the 221 couples invited, 97.8% agreed to participate at time 1 and 215 accepted to be reevaluated 1 year later. At time 2, a participation rate of 38.1% was obtained ($n = 82$ couples). Eight couples without information on the outcome variable were excluded from these analyses, so the final sample comprised 74 couples. No significant differences were found regarding psychosocial, demographic and reproductive characteristics and willingness to donate embryos for research between the patients included in the analysis and those who did not participate at time 2.

At time 1, two trained interviewers conducted face-to-face interviews with the couples, using structured questionnaires. Willingness to donate embryos for research was assessed by the question: "[When you are no longer using your embryos for your own treatment...] Did you consent/Would you consent to the use of your embryos in scientific research projects?". Data on sociodemographic characteristics (age, education level, country of origin, religion, household monthly income) reproductive and obstetric history (parental status, duration of infertility, number of previous cycles, and reasons for using IVF-ICSI), and on the importance attributed to embryo research was collected at time 1. Parental status was categorized as "children" and "no children", based on whether at least one member of the couple had a child. Religious belief was categorized as Catholic: "yes" or "no", taking into account the high prevalence of the

Key Message

Willingness to donate embryos for research is dynamic among patients undergoing in vitro fertilization. The importance of psychosocial and reproductive factors, and time, in explaining variations in decision-making regarding embryo donation is highlighted, with implications for ethics in clinical practice. The idea that informed consent should be signed after the infertility treatment is completed is reinforced.

Catholic religion in Portugal (15). The importance attributed to human embryo research was measured through the question: “How important is research with human embryos for you?”. The original scale had the following categories: “very important”, “important”, “little important”, and “not important”. As all participants answered “very important” or “important”, the variable was dichotomized into these two categories. The two main reasons underlying the decision on embryo donation for research were assessed through one open-ended question.

Data on anxiety (state and trait), depression, social support, and partner relationship were collected through self-administered questionnaires completed individually. The State-Trait Anxiety Inventory (16) is composed of two scales of 20 items each, trait (a permanent condition of anxiety) and state (anxiety in a specific situation), on a four-point Likert scale (scale range: 20–80). The Portuguese State-Trait Anxiety Inventory (17) revealed good internal consistency ($\alpha = 0.93$ for the State Scale and $\alpha = 0.89$ for the Trait Scale). The Edinburgh Postnatal Depression Scale (18) consists of 10 items on a four-point Likert scale (scale range: 0–30) and presented good internal consistency ($\alpha = 0.85$). The Edinburgh Postnatal Depression Scale is reliable for the evaluation of depression symptoms in the prenatal and postnatal periods (19). The Multidimensional Scale of Perceived Social Support (20) measures the perceived adequacy of social support received from a significant other, family, and friends, through 12 items. Respondents reported their agreement on a seven-point Likert scale (scale range: 12–84) (α [total scale] = 0.88). The Relationship Questionnaire (21) comprises 12 items on a four-point Likert scale and assesses two independent dimensions of the partner relationship: the positive relationship subscale, including a sense of support and care, as well as affection, closeness, and joint interests and activities; and the negative relationship subscale, which included anxiety, irritability, and criticisms. The questionnaire presented good internal consistency: $\alpha = 0.79$ (total scale), $\alpha = 0.90$ (positive subscale) and $\alpha = 0.72$ (negative subscale).

At time 2, self-administered questionnaires to be completed individually were sent by mail to the couples who agreed to participate. These questionnaires included the same question regarding willingness to donate embryos for research, one item about parental status as well as the self-administered questionnaires for collecting data on anxiety, depression, social support, and partner relationship.

Ethics approval was granted by the Ethics Committee for Health of the Centro Hospitalar de S. João on 11 March 2009. All participants formalized their collaboration through a written informed consent form according to the World Medical Association’s Declaration of Helsinki.

Statistical analysis

Willingness to donate embryos for research was described according to the psychosocial, demographic, and reproductive factors, and the importance attributed to embryo research, stratified by time of evaluation. To assess the association between the different factors and willingness to donate embryos for research, at time 2, model 1 was performed. Data were adjusted for the decision at baseline to observe if the effect of each variable was independent of willingness to donate at time 1. After this, we measured the effect of time on willingness to donate embryos for research (model 2). Generalized Estimation Equation models with exchangeable correlation structure, within-couple (model 1) and couple and time (model 2), were performed. The Generalized Estimation Equation model estimates the correlation between the opinion of women and men within a couple. To estimate the Relative Risks (RR) and the corresponding 95% CI, a log link function with a Poisson distribution was used. The analyses were conducted using the R Software (2013) and the GEE package, version 4.13-18.

Answers to the open-ended question about the two main reasons to be willing to donate embryos for research were synthesized into categories following a priori coding (i.e. categories were established before data analysis), according to those proposed in a recent systematic review regarding the reasons to donate and not to donate embryos for research (22), and following Stemler’s protocol for content analysis (23). The first and last authors (CS and SS, respectively) independently classified the reported reasons and disagreements were resolved by consensus. Reasons to be willing to donate embryos for research were analyzed according to the following categories: a wish to contribute to improve health, IVF treatments and research; helping others; positive views about research and the medical system; and the perception of such a decision as better than the destruction of embryos. Reasons to be unwilling to donate embryos for research were analyzed according to these categories: the perception of risks; lack of information about the research projects using human embryos; conceptualization of embryos in terms of personhood; having a baby is the priority.

Results

Table 1 describes willingness to donate embryos for research according to the participants’ psychosocial, demographic, and reproductive characteristics, by moment of evaluation. The majority of patients agreed to donate embryos for research (86.5% at time 1 and 73.6% at time 2). However, a significant decrease in couples’

Table 1. Willingness to donate embryos for research according to participants' psychosocial, demographic, and reproductive characteristics, by moment of evaluation.

	Embryo donation for research			
	Time 1		Time 2	
	Yes n (%)	No n (%)	Yes n (%)	No n (%)
Overall	128 (86.5)	20 (13.5)	109 (73.6)	39 (26.4)
Age (years)				
≤35	73 (88.0)	10 (12.0)	59 (71.1)	24 (28.9)
>35	55 (84.6)	10 (15.4)	50 (76.9)	15 (23.1)
Education level (years)				
≤12	75 (85.2)	13 (14.8)	71 (80.7)	17 (19.3)
>12	53 (88.3)	7 (11.7)	38 (63.6)	22 (36.7)
Country of origin ^a				
Portugal	114 (89.1)	14 (10.9)	95 (74.2)	33 (25.8)
Other	6 (54.5)	5 (45.5)	8 (72.7)	3 (27.3)
Household monthly income ^a				
≤1000€	8 (80.0)	2 (20.0)	7 (70.0)	3 (30.0)
>1000€	118 (89.4)	14 (10.6)	98 (74.2)	34 (25.8)
Catholic				
Yes	122 (89.1)	15 (10.9)	102 (74.5)	35 (25.5)
No	6 (54.5)	5 (45.5)	7 (63.6)	4 (36.4)
Religious practice				
At least once a month	28 (82.4)	6 (17.6)	19 (55.9)	15 (44.1)
Less than once a month	100 (87.7)	14 (12.3)	91 (79.8)	23 (20.2)
Duration of infertility (years)				
≤3	54 (87.1)	8 (12.9)	40 (64.5)	22 (35.5)
>3	74 (86.0)	12 (14.0)	69 (80.2)	17 (19.8)
Previous cycles (no.) at time 1				
0	48 (80.0)	12 (20.0)	40 (66.7)	20 (33.3)
≥1	80 (90.9)	8 (9.1)	69 (78.4)	19 (21.6)
Cause of infertility				
Female	40 (95.2)	2 (4.8)	30 (71.4)	12 (28.6)
Male	46 (85.2)	8 (14.8)	37 (68.5)	17 (31.5)
Other	42 (80.8)	10 (19.2)	42 (80.8)	10 (19.2)
Parental status at time 1				
No children	116 (86.6)	18 (13.4)	101 (75.4)	33 (24.6)
Children	12 (85.7)	2 (14.3)	8 (57.1)	6 (42.9)
Parental status at time 2 ^a				
No children	-	-	56 (74.7)	19 (25.3)
Children	-	-	45 (70.3)	19 (29.7)
Importance of embryo research ^a				
Very important	100 (91.7)	9 (8.3)	18 (16.5)	91 (83.5)
Important	27 (71.1)	11 (28.9)	21 (55.3)	17 (44.7)
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
State anxiety ^b	42.64 (12.25)	45.35 (12.32)	36.43 (9.97)	35.30 (10.91)
Trait anxiety ^b	36.46 (7.53)	37.35 (8.67)	35.98 (9.47)	36.29 (11.03)
Depression ^c	7.73 (4.45)	6.79 (4.33)	6.98 (4.62)	5.49 (4.46)
	Median (P25–P75)	Median (P25–P75)	Median (P25–P75)	Median (P25–P75)
Social support ^d	75.00 (67.00–80.00)	76.50 (63.25–79.00)	72.00 (62.50–78.00)	71.00 (65.00–79.00)
Partner relationship – positive ^e	29.00 (27.00–31.00)	30.00 (29.00–31.00)	29.00 (27.00–31.00)	29.00 (25.00–31.00)
Partner relationship – negative ^f	8.00 (7.00–9.00)	8.00 (6.00–9.00)	9.00 (7.00–9.00)	8.00 (7.00–10.00)

^aThe total does not sum to 148 due to non-responses.^bLower values indicate lower anxiety symptoms (range: 20–80).^cLower values indicate fewer depressive symptoms (range: 0–30).^dHigher values indicate the perception of a better social support (range: 12–84).^eHigher scores mean that positive relationship dimensions are more present (range: 8–32).^fHigher scores mean that negative relationship dimensions are more present (range: 4–16).

willingness to donate embryos for research over time was observed ($RR_{\text{time}} = 0.85$; 95% CI 0.76–0.95).

More than one-fifth of participants changed their opinion regarding embryo donation for research ($n = 33$ of 148): 26 changed from donation to non-donation and seven changed from non-donation to donation. Overall, change happened in 25 couples. Among these couples, change happened in both members of the couple in eight cases: three couples changed from non-donation at time 1 to donation at time 2; five couples changed from donation at time 1 to non-donation at time 2. Among the remaining 17 couples, only one member of the couple changed his/her opinion: seven women and nine men changed from donation at time 1 to non-donation at time 2; and 1 man changed from non-donation at time 1 to donation at time 2 (data not shown).

A higher education level [adjusted RR (RR_{adj}) = 0.79; 95% CI 0.64–0.96], considering research on human embryos to be important (vs. very important) ($RR_{\text{adj}} = 0.59$; 95% CI 0.39–0.85) and practicing a religion less than once a month (vs. at least once a month) ($RR_{\text{adj}} = 0.73$; 95% CI 0.53–1.00) seemed to be associated with higher probability of being unwilling to donate embryos for research at time 2 (Table 2). These effects were independent of willingness to donate embryos for research at time 1. No association was found between the psychosocial factors (anxiety, depression, social support, and partner relationship) and changing willingness to donate embryos for research (data not shown).

Education level, religious practice, and the importance attributed to embryo research showed an interaction with time (Table 3). Less-educated participants (≤ 12 years of education) did not have a significant evolution on willingness to donate over time, but more educated participants (> 12 years of education) appeared to be less frequently willing to donate embryos for research over time ($RR_{\text{interaction}} = 0.77$; 95% CI 0.63–0.95). Moreover, those with a more frequent religious practice did not change their willingness to donate embryos over time, but participants whose religious practice occurred less than once a month seemed to be less willing to donate embryos at time 2 ($RR_{\text{interaction}} = 0.75$; 95% CI 0.56–1.00). Finally, those who considered research with human embryos to be very important kept their willingness to donate embryos for research, whereas those who considered research to be important seemed to be less frequently willing to donate embryos for research over time ($RR_{\text{interaction}} = 0.70$; 95% CI 0.50–0.98).

Participants who justified willingness to donate embryos for research at time 1 based on reasons such as contributing for scientific progress, human health, and improvements in IVF treatments; the desire to help others; or by feelings of “reciprocity” towards science and

Table 2. Crude and adjusted relative risk (RR) for the effect of sociodemographic and reproductive factors on the willingness to donate embryos for research, at time 2.

	RR – Crude (95% CI)	RR – Adjusted (95% CI)
Age (years)		
≤35	REF	REF
>35	1.11 (0.91–1.36)	1.13 (0.93–1.37)
Education level (years)		
≤12	REF	REF
>12	0.80 (0.64–1.00)	0.79 (0.64–0.96)
Country of origin		
Portugal	REF	REF
Other	1.11 (0.74–1.65)	1.30 (0.87–1.93)
Catholic		
Yes	REF	REF
No	0.96 (0.64–1.44)	1.15 (0.81–1.63)
Religious practice		
At least once a month	REF	REF
Less than once a month	0.71 (0.50–1.01)	0.73 (0.53–1.00)
Duration of infertility (years)		
≤3	REF	REF
>3	1.24 (0.97–1.60)	1.25 (0.98–1.59)
Previous cycles (n)		
0	REF	REF
≥1	1.18 (0.92–1.51)	1.10 (0.89–1.37)
Cause of infertility		
Female	REF	REF
Male	0.96 (0.70–1.32)	1.02 (0.77–1.36)
Other	1.13 (0.85–1.50)	1.24 (0.95–1.62)
Parental status – time 1		
No children	REF	REF
Children	0.84 (0.51–1.39)	0.85 (0.54–1.32)
Parental status – time 2		
No children	REF	REF
Children	1.16 (0.87–1.56)	–
Importance of embryo research		
Very important	REF	REF
Important	0.53 (0.35–0.80)	0.58 (0.39–0.85)

All the variables were adjusted for the willingness to donate embryos for research at time 1.

medicine, more often kept their initial positive attitude towards embryo donation for research at time 2. Those who first donated embryos for research considering that option as “better than waste” more frequently changed their opinion towards non-donation.

The majority of participants who were unwilling to donate embryos for research at time 1 due to the conceptualization of embryos as a “child”, a “baby”, or a “living being” did not change their attitude towards donation over time. Most of those who reported the priority “to have a baby” as a reason not to be willing to donate embryos at time 1 changed to a more favorable opinion towards donation, mainly the participants who had babies or became pregnant in the meantime.

Table 3. Effect of time on the willingness to donate embryos for research and the respective interactions.

Willingness to donate	Relative risk (95% CI)
Model without interaction	
Time	
1	REF
2	0.85 (0.76–0.95)
Model with the interaction for time and education level	
≤12	REF
>12	1.02 (0.94–1.11)
Time	
1	REF
2	0.94 (0.84–1.06)
Time*education level	0.77 (0.63–0.95)
Model with the interaction for time and religious practice	
At least once a month	REF
Less than once a month	0.97 (0.82–1.02)
Time	
1	REF
2	0.91 (0.82–1.02)
Time*religious practice	0.75 (0.56–1.00)
Model with the interaction for time and importance of embryo research	
Very important	REF
Important	0.81 (0.70–0.94)
Time	
1	REF
2	0.92 (0.82–1.03)
Time*importance of embryo research	0.70 (0.50–0.98)

Discussion

This study showed that more than one-fifth of the participants changed their opinion about embryo donation for research in a 12-month follow up, with change mostly occurring from donation at time 1 to non-donation at time 2. Disagreements between partners' opinions at follow up were found among 17 couples.

In addition, it identified factors eventually associated with this change towards non-donation: being more educated, practicing a religion less than once a month, considering research with human embryos to be important, and first considering that donation for research was better than wasting embryos. This study also identified patients who changed from being unwilling to donate, at time 1, to being willing to donate embryos for research at time 2. This type of change was mostly present among couples whose priority at time 1 was to have a baby and who got pregnant in the meanwhile. From the participants who were unwilling to donate embryos for research at time 1, those who performed at least one previous cycle were significantly more willing to donate embryos for research at time 2.

These achievements generate a hypothesis for further study, to contribute to the development of patient-centredness in infertility care at two levels. First, data from this study call attention to the need to launch a debate on what are considered widely acceptable timings to request informed consent. The existence of change in the willingness to donate embryos for research supports the idea of a two/three-stage process to obtain full informed consent, as suggested by other studies (10,11). Moreover, it reinforces the argument that informed consent should be signed only after the infertility treatment is completed, in accordance with the recommendations of the Ethics Committee of the American Society for Reproductive Medicine (3). This study also draws attention to the fact that implementing good quality infertility care guided by patients' characteristics, values, preferences, and needs (24) calls for considering the factors and reasons underlying couples' willingness to donate embryos for research over time as a topic to be included in the guidelines for psychosocial care in infertility and medically assisted reproduction.

This longitudinal quantitative study shows an association between willingness to donate embryos for research over time and the education level, religious practice, and the importance attributed to human embryo research. A higher level of education is a predictor of support for science and technology (25). However, the influence of education can be moderated by the individual's interest in science and medicine (26). This appears to be also the case with decision-making on embryo donation. A recent systematic review about the factors associated with the donation and non-donation of embryos for research among patients undergoing IVF shows that valuing the expected societal benefits of research on human embryos for society, patients undergoing IVF and other individuals is associated with being more prone to donate embryos for research (22). The influence of religion should be further explored, taking into account its possible relation with this ethically challenging decision, namely through the couples' conceptualization of embryos (27). It may play a role independent of frequency of attendance, and the predominantly Catholic culture in Portugal (15) may influence embryo disposition.

This study provided longitudinal data about willingness to donate embryos for research, while controlling for the effect of willingness to donate at time 1. Being conducted with couples, it allowed the inclusion of variables related to partner relationship, evaluating its association with willingness to donate embryos for research as well as with the role of other psychosocial variables not previously studied, such as anxiety, depression, and social support. Although no significant associations were found between willingness to donate embryos for research over time and

anxiety, depression, social support, and partner relationship, there is a need for more studies in other contexts, and including different measures of these variables, to validate these results. Also, the fact that there is no research project with human embryos being currently developed in Portugal calls attention to the level of informed choice regarding the willingness of couples undergoing IVF to donate embryos for research (28). In fact, ethically robust policies and practices sensitive to patients' information needs are required, including the provision of accurate information on human embryo research (28).

This study is limited by the reduced response rate in the follow up, though no differences were found regarding the psychosocial, demographic, and reproductive characteristics and willingness to donate embryos for research between those who participated and those who did not. The obtained response rate is quite similar to those described in other studies focusing on the decisions of couples undergoing IVF on embryo disposition with more than one evaluation moment (6,9,10). It has also been reported that the loss of participants is more common in studies aiming to collect data on sensitive topics (29). Notwithstanding, it would be valuable to understand the reasons underlying the non-response at time 2. Another limitation of this study is the fact that data derive from only one public reproductive medicine centre, located in a university hospital. Although this is the biggest reproductive centre in the northern region of Portugal and our sample includes couples who had already performed at least one cycle in a private centre, this means that data generalizability should be approached with caution.

In conclusion, this study reveals that the willingness of couples undergoing IVF to donate embryos for research is dynamic, changing 1 year after patients have undergone their last treatment cycle. This study also calls attention to the importance of psychosocial and reproductive factors, and time, in explaining variations in decision-making concerned with embryo donation. Further studies, with more time intervals and larger samples, should be developed. Data in this field are essential to contribute to rethinking timings for obtaining full informed consent and the additional topics that need to be addressed by guidelines for psychosocial care in infertility and medically assisted reproduction, from which decision-making on embryo disposition should not be excluded.

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